Terry Rocks the Universe - The Will to Survive

I Have Cancer

In 2018 I was diagnosed with cancer, a rare form of lymphoma that only affects the bones and bone marrow. This particular form of cancer is called Primary Bone Lymphoma and it is one of the Diffuse Large B Cell Lymphomas (DLBCL). By the time the cancer was discovered there were thirteen distinguishable cancer lesions on my long bones that had already produced fractures (13 fractures!) I was in real tough shape physically.

This is a very rare version of lymphoma. Now, let me make a brief note about medically rare situations. They are BAD. ALWAYS BAD. Think of it this way. A non-rare condition means that the medical system has a lot of experience already under its belt. They've done the trialing to figure out what works, how to assess the uniqueness of each case, treated lots of patients, learned how to adjust treatments and often even have the tools and techniques ironed out to help manage healing and side effects.

In the world of rare disease, none of this information or experience exists. Instead, whether you like it or not, you become a guinea pig and they start trying out things. This trialing for me lasted three months just to determine, for certain, what type of cancer I had. That's right, it took three months of biopsies, scans, blood tests, special imaging, etc. to finally figure out, hey you have a very rare type of lymphoma called Primary Bone Lymphoma, and once they finally figured that out they knew how to treat it - sort of.

But there was a much darker side to this story that had not yet revealed itself, and this makes my story even more rare, a unique genetic situation that has only recently been recognized as an actual scenario in real humans, not just theory. The cancer I had was a B cell cancer and as a lymphoma that means it was a cancer of B lymphocytes (which are important parts of our blood).

The cancer family mainly associated with B cells includes Leukemia, Lymphoma, and Plasma Cell Malignancies (like Multiple Myeloma) but usually they do not run in packs. If you get one of these cancers you are not that likely to get another B cell cancer. But that is not always the case and that is not my case.

But before I fill in that blank I need to cover what has already happened to me in greater detail. The first day after being diagnosed with cancer of unknown type I was put on steroids

that were very effective at stopping the bone pain, which at this time was completely out of control.

Desperate Measures

This was in September of 2018. By December of 2018 the cancer was still not typed (and not treated.) At a loss as to what to do, they stopped the steroids to quit suppressing the cancer so that it could create a biopsyable lesion (steroids are very good at suppressing cancers and are a common part of modern chemotherapy regimens).

By the end of the month the cancer had taken off very aggressively, far more aggressively than expected (Remember that talk about rare? Yeah, prime example here.) A new giant lesion burst my L4 vertebrae into pieces requiring emergency surgery. Fortunately the cancer lesion was easy to biopsy during the emergency surgery and my cancer was finally officially typed as DLBCL - Primary Bone Lymphoma subtype.

Unfortunately the L4 fracture was “the worst the consulting surgeons had ever seen” so while they were successful in securing the main channel (opened it up - patent) they were not able to correct the hi-grade bi-foraminal stenosis at L4 and as a result I have major weight lifting and bending restrictions that I have to pay very close attention to or my low back can become a major problem. But, we did finally know the cancer type so it was time for treatment.

Here Comes R-CHOP

To help paint the picture appropriately, during this time I was unable to walk on my own. A wheelchair and a 4-wheel rollator were my only means of walking even a few steps. I was either using one of these or sitting down, I could do no more.

I did not suffer that much during R-CHOP. Besides the normal large steroid doses standard with R-CHOP I was back on Dexamethasone between treatments which was the only way we could control the bone pain (with the addition of time-released hydromorphone).

At the completion of R-CHOP we were able to move me off the dex and hydromorphone fairly quickly. The bone pain was not completely gone but more localized now and overall manageable. The treating oncology group rang the bell claiming victory but nothing could have been further from the truth.

The truth is, they missed the mark by a mile. The oncology practice did NOT attempt to treat any of the after treatment side effects. Unfortunately in the US medical system this is the rule not the exception and oncologists often don't have a choice. But chemotherapy regimens like R-CHOP are not targeted just on cancer cells, they attack and kill ALL fast growing cells in the body and that can cause very complicated symptoms that are pure quality of life stealers. So there I was, in remission, a completely broken person with none of the physical, mental or emotional strength and stability I had before all this happened - and they called it me a "success."

But even beyond that, they had missed something even more important and what they missed would have the most profound effect on me, leaving me fighting a losing battle for years where quality of life was often nothing more than a figment of someone's imagination. I fell into one of the scariest medical traps of all, the "we don't know" trap.

Hopelessly Lost - Two Cancers But Only One Cure

Roll that clock back to September of 2018. One of "things" that happened that first day at the hospital when they first found the cancer was widespread speculation that I had Multiple Myeloma. My symptoms aligned with MM far more so than any other cancer (including the Primary Bone Lymphoma.)

Plasma cancers have something unique, they create a monoclonal gammapathy in the bone marrow. A monoclonal gammapathy is a collection of identical cell clones measured as a percent of concentration in the bone marrow. These are abnormal cells and the body's defenses automatically engage with them when they exist to try and kill them off.

These monoclonal gammapathies are primarily related to Plasma cancer yet I had Lymphoma and at the same time I had (and have) a monoclonal gammapathy. The oncologists simply labeled it MGUS (monoclonal gammapathy of unknown significance) and moved on. This was a big mistake and it would cost me years of pain and suffering. I continued to demonstrate "MM like" symptoms but not at a level where the current diagnostic protocol would flag it beyond just "MGUS."

That is how it was (and still is) but changes are coming. New research is connecting more dots. It's now understood that having MGUS always puts a strain on the body, its energy, immune system and more. It's also understood that our diagnostic tools do not have the accuracy needed to define more exacting disease states. The idea that MGUS itself is a treatable

diagnosis is starting to take hold in a number of places as more and more people like me are being found who needed to start MM therapy at a much earlier date.

However, from 2019 to 2026 the only answer I had was “there is nothing wrong about you that is treatable.” This is where the darkness really bled into my life, where my understanding and perspective on my reality fundamentally changed. This is the period where hope died and desperation dominated each and every day.

This was the time when I lived in fight or flight mode every single day of my life, constantly knowing that something inside me is very, very wrong and it is doing its best to kill me. For a very long time I lived in this land of no hope and it is an experience I wish I did not have because it changed me in ways I do not like and it has taught me truths I did not want to know.

I am not the person I was before all this happened, not at all the same person. That has also been very, very hard because I liked who I used to be. I liked being me. I liked my life. Moving into a seven year stretch where none of the things that defined my former reality existed anymore was terribly hard to cope with. Parts of me were broken that cannot be fixed.

Prior to the events of 2026 I was doing my best to accept the reality that I’d been left in but it was not pleasant. It mostly came down to working hard to not feel overly bad each day. Then along came my next cancer, and while things would have to get worse for a while there was a new doorway ahead for me that was ready to be a true game changer.

Plasma Cancer to the Rescue

In January 2026 I was diagnosed with a Plasma Tumor of the Clivus bone, which is a small bone at the base of the skull near all the cranial nerves. Things got really messy. I had to deal with a nasty sinus surgery to biopsy the damn thing, I had radiation that didn’t work, extreme inflammation and active necrosis from the combo surgery/rad treatments.

My quality of life dropped like a rock. Cranial nerve involvement messed up my speech, taste, saliva glans, swallowing, and chewing. Fatigue and headaches were constant, never giving me any break. I think that’s enough of that, it’s still too fresh for me to think about much.

Next PET Scan took me to Multiple Myeloma based on multiple lesions in multiple places. I have been started on, and am continuing to take, chemotherapy in the form of the very targeted Dara-VRd protocol. I have completed my first month of this treatment.

And that is where the magic answer has arisen from. It is obvious the tumors are shrinking just as they are expected to be shrinking. As the tumors shrink and inflammation falls, the cranial nerves are settling down more and more. Eating enough food each day is no longer a problem (although it remains far more complicated than in the past). More healing is on the way though.

What is most important though is the fact that I am no longer living in constant fight or flight mode. I am not living in survival mode, I am living in life mode. There is a quiet within me that I have not had since 2018. I feel like I should run down the street yelling “The war is over! The war is over! Hey everybody, the war is over!” because that’s exactly what it feels like inside me.

Granted this is early and of course, things are not perfect. I still have a lot of healing to do. The induction phase of my chemotherapy regimen is designed to drive the MM down to what is called MRD (Minimal Residual Disease) which basically means it's almost undetectable. This induction process is likely to take a total of four months or more, so I should have at least three more months of it. The maintenance process uses the same chemo agents just in lesser quantities and frequencies so there should be smooth sailing all the way.

Final Words

I can’t say for certain that everything I have written here is correct and accurate, how can any one know that? What I can say is that the last several weeks I have been able to do, think and remember things I have not been able to do in many years. That, in and of itself, is a game changer.

I also want to say that in addition to all this, because of the damage done to my body by R-CHOP I follow a very strict supplement protocol to ensure I have ample essential vitamins and a balanced gut biome. This year I added in the mitochondrial cocktail regimen which has helped with cognition and fatigue. With the MM treatment I am now functioning better at every level than I have since before starting the treatment.

That makes MM the real game changer. Hard to believe that a cancer diagnosis is giving me back my life, isn’t it? But it sure is and I can tell you true, it feels me with joy!